

SPINAL COURIER

The spinal cord disability information source for Arkansans since 1989

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New Case Manager Arrives

Johnnie Coleman has been hired to fill the new ASCC Case Manager position approved during the 2007 Legislative session. Johnnie will work out of the Little Rock Case Management office and will cover Saline, Perry, Conway and parts of Pulaski County.

Johnnie obtained her Social Work degree from Freed Hardeman University in Henderson, TN. "Johnnie has excellent clinical case management skills, assessment and intervention techniques gained while working in a variety of settings including the Florida Department of Children and



Family Service. We're fortunate to find someone with Johnnie's experience," stated Client Services Administrator Patti Rogers.

Life is very busy and oftentimes hectic with three active daughters, Tori, 14; Shelby, 13 and Kyrsten, 10. "You don't have much time for yourself when you have three daughters, two dogs and a cat," Johnnie commented. When she does find a few moments to herself Johnnie spends time running, loves to watch the Disney animated movies and collects Disney memorabilia. Johnnie, husband Art and daughters recently moved to the Cabot area.

Please join the Commission members and staff in welcoming Johnnie aboard!

Arkansas Spinal Cord Foundation Receives Craig H. Neilson Grant

The Craig H. Neilsen Foundation of Twin Falls, Idaho announced on November 26, 2007 a grant of \$40,000 to the Arkansas Spinal Cord Foundation for the Rolling Home program. These funds will augment an \$8,000 grant from the Christopher and Dana Reeve Paralysis Foundation to pilot the Rolling Home project. This project will provide 10 clients who receive spinal cord injuries in 2008 with funding for home modifications and ramping. The funds will augment the services presently provided by the Spinal Cord Commission. "We are very excited about this grant," stated ASCF President Sandy Turner. This will give us funds to truly make a difference in the lives of newly injured Arkansans and allow them to live as independently as they can in the community."

The Craig H. Neilsen Foundation was established in 2003 to provide funding to cure spinal cord injuries. They also fund programs that support the lives of people with spinal cord injuries.

The Arkansas Spinal Cord Foundation is a 501c3 not for profit organization established in 2005. The mission of the Arkansas Spinal Cord Foundation is to promote the health, well-being and quality of life of Arkansans with spinal cord disabilities. The Foundation's goal is to raise funds to support programs and services to improve the lives of Arkansans with spinal cord disabilities.

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SPINAL COURIER

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With Thanks

Donations this quarter from:

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In Memory of George Deimel Nell Deimel

ASCC accepts tax-deductible donations. Contributions are used to assist our clients through purchases of equipment and

SPINAL COURIER Letters

Questions • Suggestions • Directions • Answers

Dear Readers:

The Spina Bifida Association of America (SBAA) has updated its list of products that contain natural rubber latex. A large percent of persons with spina bifida are allergic to latex.

The list can be found on the SBAA's website at **sbaa.org** or on the ASCC website at **spinalcord.ar.gov**.

Thomas Farley ASCC Research Manager

From the Director

It's the end of an era. In late November, Dr. Stevenson Flanigan passed away at age 81. 'Old timers' will remember Dr. Flanigan. He was the Chairman of the Department of Neurosurgery at UAMS from 1967 to 1994 and operated on most of the spinal cord injury cases. Many folks would let no one but Dr. Steve look at their necks or backs. During his tenure he also served as a consultant at Hot Springs Rehabilitation Center. He was an expert neurosurgeon but also an excellent teacher, training hundreds of neurosurgeon interns and residents. Nearly one hundred of his graduates, from all over the country, attended his retirement party.

One of Dr. Steve's greatest accomplishments, at least in my mind, was helping to establish the Arkansas Spinal Cord Commission. In the early days of his UAMS tenure, Dr. Flanigan was concerned that he could put someone's spine 'back together' but there wasn't rehabilitation after surgery to help individuals regain function. In the late 1960s and early 1970s Dr. Flanigan teamed up with Mrs. Jane Smith and Dr. Shirley McCluer to put together a plan for rehabilitation in Arkansas. Their Continuum of Care plan remains in the Commission archives. With Dr. Flanigan on the medical side and Mrs. Smith on the political side, they were able to bring their plan to fruition, with the establishment of ASCC in 1975. Dr. Flanigan was the Commission's first Medical Director and established protocols that are still in place today. In my early days as Executive Director, he would often call me. "Cheryl, Steve Flanigan here..." and he would get right to the point – a service that was needed, a patient issue or a new treatment protocol that was available. I learned a lot from him.

Dr. Flanigan retired in 1994 to his vacation home in Harrison, AR. He was honored that year at our conference, and dozens of clients and healthcare providers came to thank him for his service and his personal care for them. He was a true Arkansas treasure.

Our three greatest proponents, Jane Smith, Steve Flanigan and Shirley McCluer have gone on to greater callings. Hopefully, those of us left will be able to follow their examples as spinal cord disability advocates in Arkansas.

Cheryl L. Vines

educational resources. To make a contribution, please contact the ASCC at **501-296-1788** / **1-800-459-1517** (voice) / **501-296-1794** (TDD), or send your donation to:

AR Spinal Cord Commission 1501 N. University, Suite 470 Little Rock, AR 72207

ASCC Conducts Satisfaction Survey

Every other year, the Commission conducts a Client Satisfaction Survey. The survey provides feedback about the services we presently provide and helps us plan for future services. While we cannot ask each of our 2,600+ clients to respond, we mailed surveys to a representative sample consisting of one-fourth of our total client population. This year, an external company, Camco+ conducted the survey.

Here is a summary of the major results of the survey:

Overall, 23% of the clients who received a survey returned it. The respondents were reflective of our entire client population regarding gender, type of disability and age.

Eighty percent of the respondents depend upon Medicaid and/or Medicare as their primary health insurance.

Forty-five percent receive personal care services in their homes with most clients receiving less than 50 hours of assistance per week. While the majority of personal care services is reimbursed by state or federal programs, 28% of clients pay themselves or have unpaid help.

Respondents ranked the three most important services provided by ASCC as: 1) Case Management, 2) Purchased services and 3) *Spinal Courier* newsletter.

While about 20% of respondents were interested in ASCC sponsored activities such as educational con-

ferences, social activities, support groups and internet chat rooms, over 50% said they were very unlikely to participate in any of those programs.

The *Spinal Courier* newsletter received high marks; 94% of respondents reported that they read the newsletter. The ASCC website was less utilized even though about 60% of respondents reported they had Internet and email access. Internet access was up about 10% over the survey in 2005.

For clients who had received purchased services in the past year, 92% felt the item purchased (wheelchair, cushion, home modifications, etc) was of good or excellent quality and 78% believed the item was provided in a timely manner.

Generally, respondents were pleased with services provided by their Case Manager. Seventy-two percent reported their Case Manager was timely in providing services and 48% give their Case Manager an "A" and 26% gave a "B" in knowledge of spinal cord disability and resources; only 4% gave an "F."

Overall, 83% of respondents were "very or somewhat satisfied" with ASCC services.

The most common needs or concerns included: 1) transportation, 2) obtaining needed equipment and repairs, 3) personal care assistance, 4) getting advice/information, and 5) more frequent visits from their Case Manager.



Deirdre Sheree Massey.

West Memphis Welcomes Deirdre Sheree Massey

Deirdre Sheree Massey has joined the ASCC staff as a member of the administrative staff in the West Memphis office. Sheree is a recent graduate of Arkansas State University with a B.S. in Business Administration. She has previous experience working with people with disabilities and has demonstrated she has a huge heart for people who need help.

Sheree states that she is looking forward to learning all aspects of her job. She also hopes to conquer her nemesis, the dreaded typewriter, in a short period of time. According to ASCC Case Manager, Sharon McCoy, "Sheree has already proven herself to be a valuable assistant who is resourceful, focused and totally organized."

Please join us in welcoming Sheree to the Arkansas Spinal Cord Commission. Sheree can be contacted at **(870)** 735-4725.

UAMS-Partners Submits Report to CDC on 2005 Spinal Bifida Grant

The University of Arkansas for Medical Sciences, Partners for Inclusive Communities has submitted its final report to the Centers for Disease Control and Prevention on the study of Secondary Conditions in Arkansas Children with Spina Bifida. The grant was conducted in 2005 in cooperation with the Arkansas Spinal Cord Commission.

The 84 page report summarizes the major findings, includes a copy of the survey questionnaire and a list

of references. The full report can be downloaded from the ASCC website at **spinalcord.ar.gov** or the report is available for loan from the ASCC Shirley McCluer Resource Center. Call Allison at **501-683-1124** to reserve your loan copy.

SPINAL COURIER — 3

Prevention of Methicillin-Resistant Staphylococcus aureus (MRSA) Infection

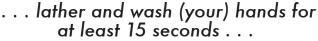
By Tom Kiser, M.D., ASCC Medical Director

Methicillin-resistant Staphylococcus aureus (MRSA) infection is in the news and on the minds of many of us in the healthcare profession. Staphylococcus aureus, often referred to as "staph," is a common bacterium carried on the skin and in the nose of healthy people. Staphylococcus aureus can cause a wide variety of infections ranging from a skin infection to more serious systemic infections like pneumonia. Some staph bacteria are resistant to common antibiotics called beta-lactams. MRSA is resistant to beta-lactam antibiotics. which include methicillin and other common antibiotics such as oxacillin, penicillin and amoxicillin. Twenty-five to thirty per cent of the population is colonized (i.e. bacteria is present but not causing an infection) with staph but only 1% is

colonized with MRSA.

basic infection-control principles were contributing factors in most of these outbreaks.

Community-acquired MRSA is transmitted from person to person via contaminated hands; sharing towels, clothing, personal hygiene items, sports equipment, or intravenous syringes and participating in contact sports. CA-MRSA infections are usually skin or soft tissue infections accompanied by fever, swelling, pain, purulent drainage, or warmth. MRSA skin lesions are frequently confused with spider bites by patients and healthcare providers. Less commonly, CA-MRSA infections can present as more serious or invasive infections. such as bloodstream infections. pneumonia, or bone infection. If



Staphylococcus aureus resistance to penicillin developed shortly after penicillin's introduction in the 1940s. When Methicillin, a semi-synthetic penicillin, was introduced in 1961, less than a year later MRSA was reported. Today hospital-acquired (HA)-MRSA is very common; about 50% of S aureus isolated from intensive care units (ICUs) and approximately 40 percent outside ICUs in the United States is MRSA. In 1982 the first reported incidence of MRSA outside of a hospital setting was found among intravenous drug users in Detroit. The emergence of community-acquired (CA)-MRSA is increasing in incidence and causing outbreaks in several well-defined populations, such as children, incarcerated persons, and participants in team sports. A lack of personal hygiene and a lack of

you develop a skin infection or an illness that is not responding to the usual remedies, the diagnosis of CA-MRSA should be considered. Risk factors for HA-MRSA are recent hospitalization, injected drug use, or indwelling catheters, while the risk factors for CA-MRSA are crowded living conditions, recent incarceration, poor hygiene, or being a member of a sports team. The main mode of transmission, however, is via hands contaminated by contact with MRSA.

To prevent or decrease your risk of infection it is important to follow basic infection control procedures:
1) hand washing - lather and wash hands for at least 15 seconds (alcohol-based hand cleansers are also helpful); 2) keep cuts and scrapes clean and covered with a bandage until healed; 3) avoid



ASCC Medical Director Tom Kiser, M.D.

contact with other people's wounds or bandages; 4) avoid sharing personal items.

Staph and MRSA infections are treatable with antibiotics, but cultures may be needed to direct your physician to the antibiotic that will be most effective. Many staph infections will need to be treated by draining the abscess or boil and may not require antibiotics, but this should only be done by a healthcare provider. If you are given antibiotics, take all of the doses, even if the infection

appears cured, unless your physician tells you to stop taking it. Do not share antibiotics with other people or save unfinished

antibiotics to use at another time. This is how resistant strains to antibiotics can develop.

The Centers for Disease Control and Prevention (CDC) makes the following recommendations for people with MRSA infections: caregivers should wash hands with soap and water after physical contact and before leaving the home; towels used for drying hands after contact should be used only once and then washed; disposable gloves should be worn when working with body fluids and hands should be washed after removal of gloves; linens should be cleaned routinely and when soiled with body fluids; and you should notify your physician and healthcare providers that you are colonized with MRSA. For more information go to the website www.cdc.gov.

Physical Activity and Exercise: Getting Started

Happy New Year!

At this time of year, we make new year's resolutions. For many of us, those resolutions include exercise or physical activity. Even if it isn't your resolution, physical activity is an important part of every person's life. Americans, in general, are becoming more sedentary. One in three adult Americans is overweight. We are becoming a generation of 'couch potatoes.' In doing so, we have put ourselves in physical danger of heart attacks, strokes, high blood pressure and joint damage.

People with spinal cord disabilities often believe that since parts of their bodies do not move, they do not need exercise or physical activity—that they are 'confined' to an inactive lifestyle. Nothing could be further from the truth! Everyone needs exercise—especially people with physical limitations such as spinal cord injuries! The activity may be different, but it is just as important, in order to maintain your health! The old adage, 'use it or lose it' is true!

Physical activity, even just a few minutes a day, is one of the most important things that you can do to stay healthy! The hardest part is getting started!

Maintaining Physical Activity After Spinal Cord Injury

A spinal cord injury affects your life in many ways, as you well know. While you were in rehabilitation, you were likely very active through your physical and occupational therapy. But once you come home and it is up to you to schedule and maintain a physical activity schedule it gets more difficult! If you were physically active before your injury, you may enjoy the chance to be active again. If you were a 'couch potato' before, starting a physical activity program may be a challenge but one that you can definitely accomplish. Maintaining your physical activity

is just as important as your bowel, bladder or skin care. You need to find a way to work it into your dayto-day life! Once you get started, it will become part of your routine. It is never too late to start physical activity.

Before You Start An Exercise Program - Consult your Doctor

It is advisable to talk with you Doctor before you start any exercise program. While the doctor will probably not be able to help you with designing a program, he or she can tell you about any exercises you should not do because of medical problems such as skin or musculoskeletal issues. This is especially important if you have had shoulder problems, heterotopic ossification or some other secondary condition. You may also want to discuss any problems with breathing, blood pressure or dizziness as well as medications. The doctor may also be able to help you monitor weight changes, since wheelchair scales are hard to find!

Set Reasonable Goals

Don't expect to be able to push a mile or lift 20 pounds the first time you try. It will take a while to get to where you want to be. Set short and long-term goals. Usually, if you set short-term goals, they will lead to long-term goals.

Setting goals doesn't have to be a detailed process—it can be as simple as writing down what you want to accomplish or telling your plan to a friend or family member. Often working with another person helps us meet our goals. Their goals may be different from yours, but by sharing them, you can help each other to stick to the plan.

Examples:

Short-Term Goals

• I will push out to the mailbox every day this week

• I will do 10 minutes of the aerobics tape by the end of the month.

Long-Term Goals

- By September 1, 2008, I will be able to push in the Healthfest 5K run.
- By June 1st, I will push around the block 3 times a week.
- By the end of the year, I will be able to make 60 percent of my free throws

Progress Slowly

Physical fitness is not something you can accomplish over night. If you try too much, too fast, you may over do it, be sore and have to stop. Start at a level that is easy to accomplish and work up, gradually increasing the time and intensity of your physical activity. You may start out working out 10 minutes a day; when that is comfortable (after a week or two), add 10 more minutes. When you get to 30 minutes, you may want to make the activity harder (by adding weight, resistance or increased skill) than by adding a lot more time.

Example:

Week 1 - follow wheelchair aerobics tape for 10 minutes

Week 3 - follow wheelchair aerobics tape for 20 minutes

Week 5 - follow wheelchair aerobics tape for 30 minutes

Week 7 - follow wheelchair aerobics tape for 30 minutes with 1 lb wrist weights

Make Exercise Convenient

Make physical activity and exercise a part of your daily routine. Find a place and time that fits with your regular schedule. If you are a late riser, don't plan to do aerobics at 6:00 a.m. - you're defeating your-See Physical Activity on page 7

SPINAL COURIER — 5

Up Close and Personal: Dee Welsh

This is the latest in a series of articles profiling the ASCC Case Managers.



Time flies when you are an ASCC Case Manager busy returning phone calls, ordering equipment, making home visits and getting to know all of the 190 clients on your case load. Dee Welsh began her duties as a Little Rock Case Manager last January and would certainly agree that this past year has gone by at warp speed. Although Dee has been an ASCC employee for 14 years, her previous position was spent in the Research and Statistics department—a more quiet setting.

Dee obtained her bachelor's degree in Social Work from the University of Arkansas in Fayetteville. She currently provides services to the individuals in Lonoke, White and part of Pulaski County. "Dee is tenacious when it comes to advocating for her clients. She will search diligently until she finds the appropriate service to meet her clients needs," commented Client Services Administrator Patti Rogers.

Dee also works part-time at the Arkansas Arts Center where she enjoys helping a wide variety of visitors including Jermaine Taylor and was able to get his autograph. Dee enjoys attending horse shows, watching fantasy and science fiction movies, listening to music and reading. She lives in west Little Rock with her Siamese cat. Dee has two grown daughters, Maren, age 25 and Jayce, age 23.

PROFILE:

Date And Place Of Birth: January 1, 1948, in El Dorado, AR.

Family Members: Two daughters, Maren and Jayce, and, of course, the Monster Cat who delights in biting the hand and arm and leg that feeds her!

If I Did Not Live In Arkansas, I Would Want To Be: In Australia.

I Absolutely Will Not Eat: Raw onions and cucumbers (it's just awful how they ruin the taste of everything they touch).

One Thing People Would Find Surprising About Me Is: I grew up (literally!) in a movie theatre. My family owned theatres in El Dorado and in Natchez, MS, and my baby bed was upstairs near the projectionist booth. I learned to count by making change in the concession stand.

My Favorite Movie Is: Oh, so hard to say—lately, The Pirates of the Caribbean trilogy; older movies, almost anything with Rex Harrison, Errol Flynn, Jimmy Stewart, Clark Gable or Cary Grant.

My Favorite Song Is: Another hard call—I love classical, Broadway and movie soundtracks, Celtic, folk, jazz and rock. Probably (at the moment, since I saw it recently) the sound track to Cats.

I Am Most Comfortable With People Who: Are laid back and comfortable with themselves.

My Favorite Pastimes Are: Reading fantasy and mystery novels, going to art museums, playing in the flower bed, and watching family and friends compete in horse shows.

The Best Advice I Ever Received Was: My grandmother always told me, "Do your best—that's all you can do."

My Favorite Saying Is: Perseverance furthers. (I Ching)

I Knew I Was Grown Up When: I went to Brooklyn and got my own apartment.

The One Thing I Always Wanted To Do But Have Never Had The Chance Was: Travel to Ireland, Europe, Japan and, I guess, just most of the globe.

One Word To Sum Me Up: Persistent.

Physical Activity

Continued from page 5

self before you start. However, it is good to exercise in the morning when you can, as it stimulates your system and gives you energy for the day. Strenuous exercise just before bed may affect your sleep patterns. Again, exercising with someone increases motivation and is more fun than exercising alone. If you plan to leave home for exercise (at a gym or YMCA), collect all of the items or equipment that you need and keep them in a bag or in the car, so that you are always ready to go. Coordinating exercise with a routine activity will also help you do it. For example, lift weights while you watch Oprah or do range of motion before you get out of bed each morning - it will become part of your routine!

Enjoy Yourself!

We all have a tendency to stick with those activities that are fun or that we get some pleasure from doing. If your physical activity program is a drudge, you are not likely to stick with it. Think of things you like to do and figure out how to add more physical activity to them. Pick physical activities that fit your lifestyle - whether it is sports, games, the outdoors or just a chance to visit. Involving other people will help. Shoot baskets with your son or daughter after school or take a stroll with a friend in the evening. Vary your activities (walk a different path, take a different class) as much as you can.

The most important thing is to GET STARTED!

Several exercise DVDs for persons with spinal cord disability are available for loan from the ASCC McCluer Resource library. Contact Allison at **1-800-459-1517** to borrow one.

Next issue:

What kind of exercise do I need?

Getting Physical

By Nick Masullo

My relationship with my body has changed. I was always a physical person—a cyclist, a rollerblader, a certified rollerblade instructor, an avid ice skater, hockey player, Special Olympics ice-skating coach. Before my town had paved trails, I traveled all around the country to skate on trails from Florida to Washington State, from Central Park to Golden Gate Park and many places in between. I am glad that I didn't miss opportunities to exercise my body. I have no regrets about that.

Strangely, I always had a kind of affinity for people in wheelchairs. I don't know why that was. Part of it was my love affair with wheels. I wondered sometimes what it would be like to be in a wheelchair. When I was a volunteer at the ice rink at the Jones Center, I was always drawn to the kids in wheelchairs. A class would come in to use the ice, and there would be a kid in

a wheelchair with his or her face pressed against the Plexiglas. I would always ask those kids if I could push them around the ice. They seemed thrilled for me to do so.

I still like my body. I look down on it, and it looks like a perfectly good one; it just doesn't work. I can no longer move my legs. I am rapidly losing function from the waist up. I have no regrets. I wasted no opportunity to use my body while it was functional. I take great joy in my caregiver using my bicycle and skates. Now I move on a different kind of wheels. I haven't been able to bring myself to go to the ice rink. If I do, maybe someone will push me.

(Nick is an award-winning songwriter and writer with quadriplegia from advanced multiple sclerosis. His friend Jeanie can understand his speech and type his dictation.)

Arkansan Authors Book about Spinal Cord Injury



Carolyn Boyle autographes her book at a recent signing.

A Complete Plain-English Guide to Living with a Spinal Cord Injury, Valuable Information From a Survivor is a book by Carolyn Boyles recently published by iUniverse.

Carolyn, a long-time spinal cord injury survivor, presents solid, factual information and real world advice about living and thriving with a spinal cord injury in her 538 page book. Divided into 106 topics, each 2-3 pages long, it is easy to read a section in a few minutes.

Her book is available for loan from the ASCC Shirley McCluer Resource Center–call **Allison** at **501-683-1124** to check it out for two weeks. The book is also available for purchase, \$32.95, at **iUniverse.com** and **Amazon.com**.



The squeaky wheel . . . gets the grease! This column is about grease—things that make life for persons with spinal cord disability go smoother and ease your way in the world. "Things" can be hints, equipment adaptations, innovations, tricks-of-the-trade, procedural shortcuts, life experiences, or things you "should have done but didn't."

Robert Fitzpatrick of Batesville, Arkansas relates his experience in dealing with vendors about medical supplies.

Ever had problems with medical supplies? Have you ever had problems with ordering, receiving, waiting on back orders, getting the wrong stuff?

Have you ever felt like the guy on the other side of the desk or end of the phone didn't have a clue what you were needing or asking about?

My answer is "yes" to all of the above. That is until I found a supplier called Xtreme Medical that is based in California and also has

offices in Illinois, Massachusetts and Minnesota. Xtreme Medical is a medical supply company whose employees are fellow quads and paras. They understand fully your needs because they are dealing with the same situations as we are. They understand the importance of getting the right supplies the first time and the value of keeping up with what is new and good. They can discuss the pros and cons of various products and they understand insurance and can find out what it will and won't pay for.

You can check out Xtreme Medical at their website - xtrememedical. com or please feel free to call me at **870-793-2232** with questions or comments. My email address is robffitz@hotmail.com. I'd love it if Xtreme Medical could be more of a presence in our state and will do everything I can to make that happen. It will take more than one person to accomplish this. So, if you have any interest in this or have any questions please contact me.

We invite you to send in your helpful hint—your bit of "grease." Contact your ASCC Case Manager, write us at Spinal Courier, Arkansas Spinal Cord Commission, 1501 N. University, Suite 400, Little Rock, AR 72207 or e-mail us at courier@arspinalcord.org and put "Squeaky Wheel" in the subject line.

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